

Despite some 30 years of effort, we have made remarkably little headway where the physician-patient relationship is concerned. Although things are better than they used to be, we're still a long way from realizing the goal of shared decision-making promoted by the doctrine of informed consent.¹

Not only has progress been meager, there are signs that a backlash of sorts is under way. We now hear that "uppity" patients are demanding medically futile treatment, that they can't think straight, and that what they really need is a medicalized death. As a result, we see the emergence of three movements whose common feature is to sustain medicine's dominance of how medical technology is used: medical futility, medical ethics consultation, and physician-assisted suicide. Although the rhetoric employed in each of these movements differs somewhat, the bottom line remains the same: some things are better left in the hands of medical professionals, who know better than patients do what their wants and needs actually are.

Given that the physician-patient relationship has proven to be so resistant and resilient, one has to wonder what driving force creates and sustains physician dominance of patients. If legislation, judicial decisions, conferences, books, articles, appeals to reason and courses in the humanities don't do the trick, just what is going on here?

I think that many of us have overlooked or minimized the importance of something where relations between physicians and patients are concerned: power. As a result, we've either been naive about the prospects for reform, or complicit in perpetuating physician dominance of patients. We've either not seen what underlies relationships be-

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Patientism

by **Giles R. Scofield, J.D.**

tween physicians and patients, or succumbed to its seductive force.

I call this force "patientism." Patientism is a state of mind, a set of attitudes and beliefs about what patients do and how they should behave. Patientism is descriptive and prescriptive, a socially constructed reality that governs what comes to be 'our natural, taken-for-granted beliefs about how relationships between physicians and patients are and are supposed to be. It's a self-fulfilling prophecy, a tautology. Patients behave as they do because that is how they ought to behave; and they ought to behave that way because that's how patients do behave.

Patientism is like such other "isms" as racism, sexism, imperialism and orientalism. It is a set of attitudes and beliefs that are regarded as demonstrably or inherently true (in either event, they're incontestable) that govern relations between individuals in one group and individuals in another. The dominant group defines what members of the other group—the objectified group—are like and what their wants and needs are, essentially because members of the other group do not or cannot know what their own wants and needs are. Patientism, then, is a discourse of domination and subordination, designed with one purpose in mind: to keep each group in its proper "place." Patientism keeps physicians in a superior, dominant role, and patients in an inferior, subordinate role. That's its purpose and its logic.

If patientism exists, this would have profound ramifications for law,

ethics and the medical humanities. For patientism has nothing to do with reason, in the sense of being reasonable, sensible and fair, but with the logic of power, the desire to remain in power because of the fear of what it might mean not to be in power. Eli Sagan has aptly named the desire for power and the fear of not having it the "paranoia of domination."² If one thing is true where power, desire and fear are concerned, it is that they are virtually immune to reason. This means that the traditional beliefs we hold about the role of reason and logic, beliefs that underlie the faith we place in law and education as the means for effecting change and making progress, will not and cannot matter much in terms of reforming relations between physicians and patients.

Power rarely relinquishes itself, largely because the desire for power and the fear of not having power reflect deep-seated beliefs about the desirability of equality and the capacity for trust. People who cannot or will not trust others or who cannot or will not imagine being treated by others as equals are going to resist the suggestion or the argument that they relinquish their domination and that they trust others.³

There's no reason not to think about the physician-patient relationship in this manner. After all, one physician-ethicist has admitted that power is relevant here,⁴ and Jay Katz has spent years exploring the ways in which the power doctors attempt to wield is the product of their aspirations and their fears.⁵ Resistance

to thinking of relations between physicians and patients in terms of power, or to imagining that something like "patientism" might exist probably reflects idealized or sentimentalized beliefs and attitudes about the nature of the physician-patient relationship. After all, many of us like to think of the relationship as a caring one, and of doctors as acting out of beneficence. Of course, when we think about the physician-patient relationship in this way, we need to be clear on what it means to care and to be beneficent.

Joan Tronto recently argued that there is a political dimension to the ethic of care.⁶ Part of this concerns the asymmetries that exist between those who are in need of and those who deliver care. Just how "caring" one is depends on the extent to which someone exploits those asymmetries or treats the one needing care with equal respect, regardless of the difference in their positions. Simply put, it's one thing to believe that people are equals, and something else to act as if we are and not take advantage of the fact that we differ from one another in many respects. From what I've seen of the literature on the ethics of care, which tends to focus on caring as something that only women can and should do, the political aspects of what it means to care hasn't had a levelling influence on physicians and patients.

Just as caring is amenable to egalitarian and inegalitarian uses, so is beneficence. Beneficence is a nice, high-sounding word, but that doesn't mean that it is incapable of masking and rationalizing pernicious practices. After all, its counterpart, benevolence, rationalized imperialism and colonialism.⁷ Thus, when we use these words or think about the physician-patient relationship in these terms, we need to wonder whether they mask more than they reveal the way things are.

In what follows I intend to test my hypothesis about patientism in three areas—representation, participation and consent—to see whether

there might be something to my concerns. Then I will discuss the implications patientism has for medical ethics and the medical humanities, and for those who work in those fields.

Representing patients

Representation is so familiar and commonplace a term that we tend to believe we know what it means without thinking much about what it does and can mean.⁸ In one context, to represent an individual or a group is to depict or portray him, her or them. Such representations can create and sustain attitudes and beliefs regarding the individuals or groups so portrayed. The representations can also create and sustain relations of domination and subordination.

Consider, for example, the ways in which deaf persons often are characterized as childlike, dependent, disobedient, irresponsible, submissive, naive, incapable of thinking clearly, shrewd, unintelligent, aggressive, immature, impulsive, stubborn and temperamental.⁹ Although this list is not comprehensive and shows considerable variation, it is held together by a two distinct commonalities. First, it reflects how others view the deaf and not how the deaf view themselves.¹⁰ Second, the images created by these words is of a group that is inferior in some respect (and with respect to another group) because each of the words is a pejorative. In this sense, representing is a political act because it allows one group to depict another in a way that creates and sustains an image of superiority and inferiority, an image that is essential to a relationship of dominance and subordination.

Notice that it is not simply the words themselves, but who is applying them, how, to whom and under what circumstances that matters. For example, while it can be good for a business person to be shrewd, this term can indicate that a deaf person is wily and unreliable in dealing with others, which makes this a person

not to be trusted. To portray the deaf in this fashion is to render them inferior in the eyes of others, as a group of individuals who are or ought to be in need of help from others and who are incapable of looking out for their own interests, the trademarks of a group that is inferior and subordinate to another group.

What's interesting about the characteristics attributed to the deaf is how similar they are to the pejoratives that have been and often still are used to describe other groups that are or have been regarded as inferior in some sense. The labels of inferiority listed above are used elsewhere to suggest the inferiority of members of a given sex, race or ethnic group. The portraits of others are how they are represented to and by others. And to the extent that these representations convey the image of an individual or group that possesses "inferior" characteristics, we tend to regard them in the manner represented.

Now think of how we tend to think of patients.¹¹ How frequently are they called non-compliant (childlike and disobedient), emotional or irrational, incapable of thinking clearly, of knowing too little or too much about their condition, of being stubborn or submissive, or even of being shrewd? Patients, it seems, are incapable of acting in ways that do not reflect poorly on themselves. To be a compliant patient is to be passive and submissive, attributes that are not favored in a society that promotes the myth of rugged individualism. Yet the patient who is stubbornly independent is doomed to be regarded pejoratively also, because those are not characteristics associated with being a good, i.e., co-operative and unquestioning patient.

Similarly, although the ideal model of individual behavior is rational self-interest, the patient who coolly calculates the alternatives and wants to learn as much as possible before making the correct decision may be regarded as an obsessive-

compulsive or even as someone who is setting the physician up for a lawsuit. Patients, it seems, cannot save themselves from being regarded as inferior and subordinate, no matter how they behave.

What is also interesting about the representation of patients is that these portrayals do not come from patients themselves. It's rare for a patient to write an article that gets published in a medical journal or even in any of the many journals devoted to medical ethics or the medical humanities. (Occasionally we are treated to what it was like for this doctor or that ethicist to be a patient, but even that portrayal filters the experience through the perspective of a professional.) Where the representation of patients is concerned, then, the images we get of patients are the portraits made of patients by someone other than patients themselves. No matter how we see patients, we almost always see them through someone else's eyes, and most often through the eyes of someone whose status is "superior" to that of the patient.

Patients do not represent themselves; other represent them. And because the representations of patients most frequently are drawn from physicians' descriptions of them, we should not be surprised that the images we receive of patients reflect poorly on them. Whatever they are, patients are incapable of demonstrating the traits one must have to be regarded as the equal of those who are not patients, including physicians. This image of patients explains why patients remain unequal or non-participants in decisions affecting them. Accordingly, we now turn to the problem of participation.

Participating patients

To be a non-participant is to be powerless,¹² and vice versa. Whether a group is supposed to be a non-participant because it is powerless or is powerless because it is supposed to be a non-participant doesn't really matter. What matters

is the group and its members do not and are not supposed to speak for themselves.

Here we look at representation in a variant sense of the word, not as speaking about someone else, but as speaking for someone else. The concept of representation means that we are supposed to regard someone's speaking for another as the equivalent of that other person's words.

The concept of representation is a political and legal fiction invented to sustain the illusion of actual contemporaneous participation. The critical questions here center on who can claim to be someone else's representative and what it means to represent someone else's views. These merit examination.

Once we accept the notion that it is possible for one person to speak for another, the person who does the speaking is in a position to say what the other would say if actually present. One aspect of this is the idea of presumed consent, which rests on the idea that we know what a reasonable person would say in a given situation. And since we assume that everyone is, wants to be or should be reasonable (although just what it means to be reasonable is undefined), we can know what a reasonable person would want. This fiction enables us to justify taking courses of action with respect to patients without the necessity of their actual participation, because of the belief that we know what they would or should say if asked. The illusion of participation justifies the practice of non-participation.

The most obvious example of this is the presumption that everyone consents to cardio-pulmonary cerebral resuscitation (CPR). We assume this without any evidence to indicate that everyone would want CPR if they knew how dependent its success is on a number of factors, and with growing evidence that when patients are made aware of these circumstances they voice a preference against CPR. Based on the representation of what a "reasonable

person" would or would not want, it is possible to argue that: (1) no one would want futile CPR; (2) no patient undergoing surgery would not want CPR; and (3) relatives of recent accident victims either are incapable of consenting or would not refuse consent to experimental protocols on cerebral resuscitation. The fictionalized belief about what individuals would say becomes the justification for not asking them, thereby sustaining non-participation and powerlessness.

Representation as non-participation emerges in other ways. For example, patients rarely participate in discussions about ethics. Conferences and journals are devoted to the words of experts (those who know about patients), not the patients themselves. The various institutes and centers that address issues affecting patients don't have patients serving on their boards any more than 19th century groups concerned about slaves or the Indians allowed slaves or Indians to participate in their deliberations. Although we hear a good deal of talk about the importance of the patient's voice these days, all this has generated is an interest in ethnography and narrative, which amounts to no more than having a new expert interpret the voices of patients, i.e., to mediate what patients are saying. I don't know many patients who believe that the thicker descriptions privileged others provide of them is preferable to or a valid substitute for allowing patients themselves to tell others the meaning of their words.

Our faith in the concept of representation is so strong that when we hear from someone who advocates for patients, whether as a right-to-die spokesperson or a disability-rights advocate, we don't doubt that this person can and does represent the voice of patients, i.e., says what patients would say if they participated. As someone who has spent time in both the right-to-die and the disabilities-rights movements, I know how often those who purport to speak for each constituency fail to

represent either of them, in that they fail to indicate the breadth, variability and nuances of belief found among members of these groups. Those who purport to represent the interests of patients foster a belief in the "essential patient" that is as inaccurate and unfair to patients as it has shown to be in other contexts.¹³

Whatever the situation, the concept of representation serves to limit the participation of patients, with the result that they become less powerful. We don't hear their voices because we don't need to, and we don't need to because we think we know what they would say. Thus, patients need not actually participate; indeed, they should not do so. The concept of representation, then, justifies the non-participation of patients in decisions affecting them. So long as someone else is speaking for them, they don't need to speak for themselves; and because we can get along just fine with someone else speaking for them, they shouldn't speak for themselves.

The problem of consent

Consent is key to clinical decision-making. Its presence or absence determines whether a physician's actions are authorized or not. Thus consent either enables physicians to do as they desire, or stands in the way of those desires. For this reason, being able to determine what counts for consent lies at the core of a physician's power over a patient.

We've already seen how the concept of representation enables physicians to declare that consent exists under conditions when it actually does not, with respect to CPR. Other examples of the ways in which consent is presumed to exist, to get around the fact that it doesn't, include presumed consent to donate an organ and presumed consent to be used so that others can practice their intubation technique. What's interesting about consent is not just that it's manufactured to suit medicine's purposes, but that it's completely manipulated in contradictory ways to do that.

For example, consider the role that consent plays in decisions about medically futile treatment and physician-assisted suicide. In each instance, we're talking about dying patients for whom nothing more can be done. Where decisions about CPR are concerned, some are willing to presume consent to a DNR order, both because that's what a reasonable person would want and because patients are too upset, depressed, desperate and emotional to participate rationally in the consent process. Where physician-assisted suicide is concerned, these same patients are rational and clear-headed, which means that their consent counts for everything. The only thing that reconciles these divergent views about patients is that presumed consent to DNR and actual consent to physician-assisted suicide enable physicians to act with impunity in both cases. Thus, consent is manipulated to serve physicians' power and their professional dominance. In each instance, all that is really going on is that physicians are arguing for the model of consent that will maximize their power and minimize their liability.

Patientism and the meanings of power

At the outset I suggested that patientism is a set of attitudes and beliefs about how patients do and should behave, and that it creates and sustains an asymmetry of power in the physician-patient relationship, in which the physician is dominant and the patient is subordinate. Because that is how the relationship is and should be (in the minds of some), we should expect to see these attitudes and beliefs play themselves out in questions about representation, participation and consent. And that is precisely what we see, with the common thread being that physicians are and should remain dominant. Patients are described pejoratively, are not regarded as necessary or desirable participants, and find themselves facing a model of consent that has more to do with maxi-

mizing physician power than with realizing the goal of shared decision-making.

In talking about the role that patientism plays in relations between physicians and patients, we need to be attentive to its various manifestations, overt and covert, as well as to its subtleties. I suspect that the term patientism causes rancor in some circles, because people suppose it means something akin to lynching blacks and beating women. While patientism certainly does embrace those situations in which medical professionals abuse patients, it also embraces more subtle behaviors. As anyone will tell you, the job of improving relations between the races and sexes does not end when overt racism and sexism are eliminated, but begins only when individuals become aware that many of their taken-for-granted attitudes about members of groups reflect bias and prejudice that tend to keep those persons relegated to inferior roles. It's precisely because those beliefs are so ingrained that it is difficult to address them.¹⁴

Thus while some patientism exists because some physicians believe that they are superior to patients, or because some doctors desire domination, or because some fear being dominated, some patientism exists because some physicians are unaware of the fact that their conduct towards patients reflects the taken-for-granted beliefs about how patients do and should behave. What is taken to be innocent conduct on their part would, if dissected, reveal beliefs and attitudes that they might not subscribe to if they reflected on them.

I mention this because some may take my suggestion of patientism as reflecting the belief that all doctors are always bad and that all patients are always good. That's not my point. Obviously, the corrective for a problem created because one group or perspective is regarded as superior to another is not and cannot be that another group or perspective is superior. What I am saying is that rela-

tions between physicians and patients tend to be characterized by an asymmetry of power that creates and sustains an inequalitarian relationship, one that we would have to characterize as undemocratic.¹⁵ This asymmetry persists because of the belief that to be a patient is to hold an inferior position in the eyes of others.

Moreover, while patientism is most pronounced within the field of medicine, its existence and persistence cannot be attributed solely to the medical professions. Powerful though medicine is, it is capable of sustaining patientism to the extent it does because other members of society endorse, acquiesce in, or simply don't examine our beliefs about patients. To the extent that members of the public harbor biases about and prejudices against patients, those beliefs and attitudes allow patientism to go unchecked.

Although we might talk about the beliefs some of us hold about patients who have certain diseases, especially the types of diseases that are supposed to reflect some moral failure or fault of the patient, such a discussion would divert us from the attitudes and beliefs many of us hold about what it is or must be like to be sick or disabled, beliefs that affect how we see and respond to individuals who are sick and disabled. As those who have a serious illness or disability, especially a noticeable one, will tell you, they spend a good deal of their energy taking care of others, i.e. helping other people not feel uncomfortable about being with someone who has "something wrong" with them. Just what is it that's "wrong" with being sick or disabled?

I recall distinctly the reactions some of my colleagues and friends expressed to me when I told them that I had taken a fellowship to study the ethics of rehabilitation, which is simply a nice way of describing what's involved in the care and treatment of individuals who have suffered a catastrophic injury. A good many said that they couldn't do that;

one even said I was an "angel" (a comment about me not likely to be endorsed by many ethics consultants). At the time, I did not think much of these remarks. Now I think differently. Had I said that I was going to represent death-row inmates, work for reproductive rights, or represent the homeless (whom I call the victims of "economic cleansing"), I suspect that I would have received the slap on the back that right-thinking liberals give to one another. To say that I was going to be with the disabled, to learn about the care and treatment they receive, caught a few people off guard. Now that I am back in the able-bodied world, I notice how uncomfortable many people are about disease, disability and death. These feelings, fears and attitudes are reflected in how each of us perceives, thinks about and responds to the sick, the disabled and the dying. It is these attitudes and beliefs that give rise to patientism, and the practices and institutions that keep patients "in their place."

The solution to this problem consists partly in consciousness-raising, and efforts to establish the degree of trust and respect that characterize relations between individuals who are regarded as moral equals despite the fact that they are not equal in the empirical sense. Where patients and physicians are concerned, this means that both groups are regarded as experts in their own areas—physicians in what they know, and patients in who they are. The task that remains is to sort out what they wish to do together as equal participants in a therapeutic venture. Obviously, this is easier said than done; it is, however, doable and desirable.

From my own work with medical professionals I have found it helpful for them to imagine or relate what it is like to be a patient. This sort of work does nothing more than follow Aristotle's old maxim that those who would rule must learn what it is like to be ruled, in order that they may rule wisely and justly. There is a

vast and growing literature on the experiences physicians and other healthcare professionals have had as patients, a literature that is notable for how often this experience alters the conduct and practices of healthcare professionals towards patients.

Speaking from my own experience in studying persons with disabilities, I learned more about what it is like to be disabled from spending a morning tooling about in a wheelchair than from anything else I read or observed. Downhill, uphill, over gravel, up curbs, through doors, none of it was easy. I also realized how the presentation of merchandise on shelves presents a problem for persons with disabilities, who must ask others for assistance. The most interesting observation, however, was that children, who make direct eye contact with you, tend to think it's "cool" to be in a wheelchair, whereas adults don't know what to do, especially if they're in a car and you're trying to cross the street.

The existence of patientism has implications for medical ethics and the medical humanities, not all of which are going to be welcomed by those who work in these fields. Although scholars like to think of and portray themselves as objective, neutral intellectuals, no such bird exists. Just as scholars have promoted, acquiesced in, criticized and worked to change such practices as imperialism, racism and sexism, the same is true where patientism is concerned. While I know that it offends some sensibilities to suggest that ethics and the humanities have political content and play a role in sustaining or reducing the asymmetries of power that exists between physicians and patients, it is naive to think otherwise.¹⁶ To the extent that we are committed to the "disenchantment of the world," using reason and critical analysis to expose myths, we must scrutinize ourselves as much as we do others.¹⁷

Yet because patientism is not limited to medical professionals, re-

forming the relationship physicians have with patients will never occur until we reform the belief we hold about the sick, the disabled and the dying. After all, if a lot of us think that no one would want to live "like that," we shouldn't be surprised if social institutions regard individuals who are "like that" as a lesser form of human life. We will never begin to do things for patients, as opposed to arguing over what should or shouldn't be done to them (the vacuous debate that so-called pro-choice and pro-life advocates are engaged in), until we regard patients as individuals who deserve respectful treatment.

Can we do something about patientism? I think so. What distinguishes patientism from sexism and racism is that it's possible for someone in the dominant group, e.g., a physician, to become a patient. Indeed, one day each of us will be a patient, and a good many of us, thanks to advances in medicine, will be patients for a long time. To the extent that "isms" reflect an us-them dichotomy that enables "us" not to feel uncomfortable about how "they" are treated, this is simply foolhardy when how "we" think about patients.

One day each of "us" will be one of "them," which means that as we think and talk about the sort of care and treatment patients deserve, we should think about the sort of care and treatment that would enable and allow us to be respected as persons when we become patients. If we could do that, we would take a first step in the direction of transforming our system of care into a system that cares. I believe we can, but wonder whether we will.

Endnotes

1. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Making Health Care Decisions*. Washington, DC: USGPO, 1982; Capron AM. Informed consent in catastrophic disease research and treatment. *Univ. Pa. L. Rev.* 1974;123:340-438.
2. Sagan E. *The Honey and the Hemlock: Democracy and Paranoia in Ancient Athens and Modern America*. Princeton, NJ: Princeton University Press, 1993.
3. Luhmann N. *Trust and Power*. New York, NY: John Wiley & Sons, 1979.
4. Brody H. *The Healer's Power*. New Haven, CT: Yale University Press, 1992.
5. Katz J. *The Silent World of Doctor and Patient*. New York, NY: Free Press, 1984.
6. Tronto J. *Moral Boundaries: A Political Argument for an Ethic of Care*. New

- York, NY: Routledge, 1993.
7. Said E. *Culture and Imperialism*. New York, NY: Alfred A. Knopf, 1993.
8. Pitkin H. *The Concept of Representation*. Berkeley, CA: University of California Press, 1967.
9. Lane H. *The Mask of Benevolence: Disabling the Deaf Community*. New York, NY: Random House, 1993: 36.
10. Padden C, Humphries T. *Deaf in America: Voices from a Culture*. Cambridge, MA: Harvard University Press, 1988.
11. Gething L. Judgments by health professionals of personal characteristics of people with a visible disability. *Social Science & Medicine* 1992;34:809-815.
12. Havel V, et al. *The Power of the Powerless*. London: M.E. Sharpe, 1990: 230-96.
13. Spelman EV. *Inessential Woman: Problems of Exclusion in Feminist Thought*. Boston, MA: Beacon Press, 1988.
14. Bell D. *Faces at the Bottom of the Well*. New York, NY: Basic Books, 1992.
15. Yeatman A. *Postmodern Revisionings of the Political*. New York, NY: Routledge, 1994: 42-56.
16. Bourdieu P. *Homo Academicus*. Stanford, CA: Stanford University Press, 1984.
17. Horkheimer M, Adorno T. *Dialectic of Enlightenment*. New York, NY: Continuum, 1990.

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nurse, received \$10,000 for a three-year grant to identify children of short stature in the public schools and refer them to their doctor for evaluation. Her husband, Dr. Mark Parker, is the only pediatric endocrinologist in Charlotte, NC.

A spokesperson for the Charlotte-Mecklenburg school system approved letters sent out to parents of children identified by the school as possibly having a growth problem. Mrs. Parker has not published her findings, and Dr. Parker in response to questions said that he does not know if any of the children identified by his wife are now under his care and receiving growth hormone treatment.

One outraged parent, John Towle, told of being pressured by

Dr. Parker to give their 11-year-old son, who is short for his age, human growth hormone treatment. Mr. and Mrs. Towle are both short and feel that it is acceptable for their son, Brodie, to be short as well. They went to see Dr. Parker to rule out any other medical problems. Brodie is 50 inches tall, which is well below average, but his hormone level and growth rate are normal. Dr. Parker asked the parents how they will feel when Brodie grows up and is told that he could have been five-feet-ten instead of five-feet-six. The Towles were insulted by this and left Dr. Parker's office.

There is an ongoing controversy among endocrinologists as to whether or not it is ethically appropriate to treat a child with human growth hormone if the child is not deficient in growth hormone but is genetical-

ly of short stature. Some physicians will not treat children who have normal human growth hormone levels and others feel that if the child will be adversely affected by short stature then it is appropriate to offer the treatment. The treatments often occur over a period of several years and there are possible side effects ranging from mild discomforts to rare but notable cases of diabetes and leukemia.

There is a fundamental belief in medicine that the relationship between physician and patient should be characterized as one of trust and the physician must not have any conflict of interest when treating the patient. If the charges against these professionals are substantiated, then they have breached this time-honored trust.